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AUTHOR Hammer, Edwin K.
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ABSTRACT

Parents of deaf-blind children frequently have common needs and experience definite critical times of stress as their child matures. Parents need emotional understanding and support, information and facts, a greater degree of active participation in habilitation planning, a self image of themselves as competent and participating community members, an understanding of their role in the habilitation process, and an understanding of present and future expectations for the handicapped child. The following critical times are likely to increase parental stress: at birth or upon suspicion of handicaps, at time of diagnosis and treatment, as child nears age for school placement, as child nears puberty, as child nears age for vocational planning, and as parents age and child may outlive them. (DB)

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Families of Deaf-Blind Children: Case Studies of Stress

by

Edwin K. Hammer, Ph.D.

There is stress within any family unit into which a multihandicapped child is born. The patterns of stress may seem to be unique to each family. The reaction patterns may seem to be unique to the personalities of each family member. The question seems to be: Are there communalities which all families face and common reaction patterns which all families exhibit in their adjustment to having a multihandicapped child in the family unit? If insight into patterns of adjustment can be gained by those of us in a helping relationship, it may be possible to assist

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Dr. Hammer is Coordinator, Regional Center for Deaf-Blind Children in Arkansas, Louisiana, Oklahoma, and Texas, at the Callier Hearing and Speech Center, Dallas, Texas. Mrs. Torrie is Consultant in Social Services for the Regional Center at Callier Hearing and Speech Center. Miss Armstrong is social worker for the Houston Lighthouse for the Blind, Houston, Texas and Mrs. Yu is social worker for the Child Study Center, University of Oklahoma Medical Center, Oklahoma City. Study funded through Bureau for the Education of the Handicapped under grant OEG-0-9-536003-4093.

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the family in their adjustment of having a multihandicapped child as a family member.

Investigations of actions and reactions within the family have been carried out and are available from the literature. These studies will be reviewed as they relate to three basic categories: parental needs and expectancies, family functions, and helping services. Barraga (1966) listed six needs which parents of multihandicapped children exhibit. While these needs were presented as they related to children with cerebral palsy, they seem to generalise to needs of parents of multihandicapped children and certainly are applicable to families of deaf-blind children. These six needs of parents were:

1. Parents' need for emotional understanding and support. This need should not be interpreted to mean counseling, per se. It is more to meaning an acceptance by the professional that the feelings of frustration and guilt are the normal reaction of these parents. Mourning, as used by Wright (1960) and Cholden (1958), among others, is not limited to the reaction of the disabled person. Parents, too, go through a period of mourning the loss of the child who had been expected. Parents, too, must be allowed the

opportunity to reject the handicapped child. Parents, too, must run the range of reactions of emotions as part of the reality of the situation. Support and understanding, on the part of the professional worker, must include an acceptance of this process and not an attempt by the professional person to hurry the parents through these negative reactions.

2. Parents need information and facts. This need is most difficult to meet. Often it is not possible to know the effects of a disabling condition which the child has. It may not be possible, for instance, to define the degree of hearing loss in very young children. It may not be possible to be informative as to the visual function of a child with congenital cataracts. It is difficult for professionals to communicate with each other when the technical terms of emotional overlay, mental retardation, autism, or deafness are used, it is even more difficult to describe and be informative to a parent of a handicapped child. However, if the parents are to move from their own negative feelings, toward a realistic adjustment, they must have information and facts presented to them which will help them grasp the situation. It is this need, perhaps, that leads parents to a seeking level of adjustment. At this stage, the parents in looking

for information and facts may go from agency to agency, professional to professional, trying to find the answers. If help is to come to the parents, it must be to aid in gaining information and grasping the situational facts rather than seeking answers to questions which may not have answers.

3. Parents need a greater degree of active participation in the planning of habilitation. In the very recent past - and perhaps into the present - parents have been expected to deposit their child with a therapist or teacher and to wait passively. This surely must encourage stress - from not knowing what their role is, from not being a part of the process, from not understanding what is happening to their child. It seems logical that this passivity would lead to more stress by increased guilt, by implication that someone else must do the job, and by devaluing the parents as part of the habilitation process. This brings up a fourth need which Barraga stated:

4. Parents need to maintain an identity of themselves as parents, as participating members of the community, and as competent individuals within themselves.

Much of the stress which is observed in parents of deaf-blind children is physical stress from having the responsibility for total care of a child 24 hours a day, year in and year out. This alone can create dissolution of a family unit. Not only is there physical stress, but also there is economic stress which threatens the family structure. Time off from work to drive to appointments, increased medical costs, expenses for prosthetic devices, costs of enrollment in therapeutic settings, all place a financial burden on even the most affluent family. Social stress is also present and may range from neighbors who no longer come to the house, to grandmothers who insist that the condition did not come from their side of the family, to finding a baby sitter who will stay with the child on an occassional parents' evening out. All of these types of stress, coupled with the mental stress of guilt and uncertainty contribute to the loss of perspective of self-needs of parents.

5. Parents need a thorough and dynamic understanding of their role in the habilitation process. Parents are responsible for their children. Even though professionals may feel that they know what is best for the child, the

parents' responsibility cannot be denied. This means that parents and professionals must work together and mutually define their relationship so that neither is subordinate to the other and the goals of habilitation are accepted by both. This means that professionals must understand that they can do their thing - but that the child and parent will continue after the professional person has performed his task. I am not opposed to residential schools for exceptional children, they offer a concentration of services and facilities which cannot always be found near the child's home, however, I never cease to be amazed that professionals are confused when children are placed in residential schools and then do not have a place in the family when the residential facility wants to return the child home. If the parents' role is denied or unclear, if the family is de-valued, further stress is created which curtails the long range achievement of habilitation. Perhaps it is for these reasons that Barraga listed as a sixth need:

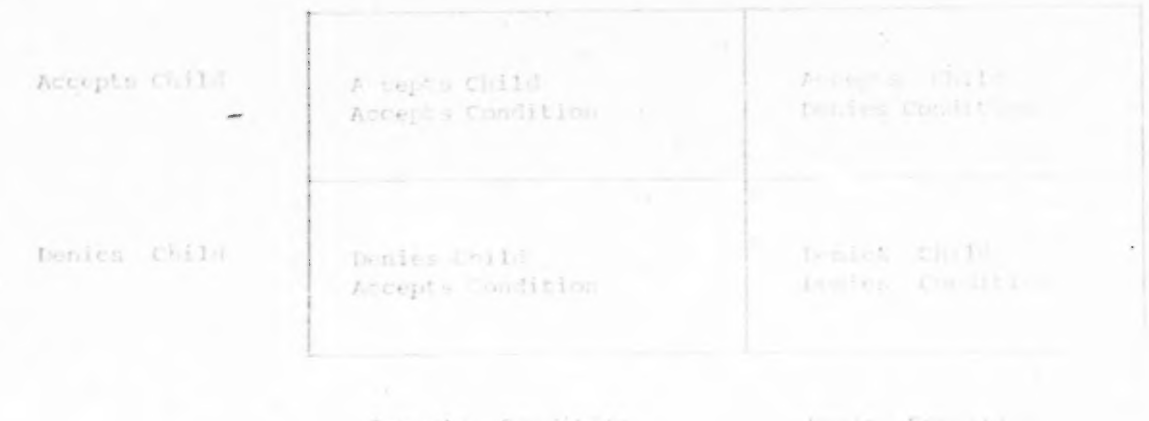
6. Parents need to know the present and future expectations of the handicapped child. The future is never certain. For the parents of a deaf-blind child, the future looms threateningly. Often they are not sure of the present.

The past has been made up of trial and error. It seems important that future expectancies be brought out of a never-never land and into some area of open communications. The reservations of all those involved should be discussed. It seems important to discuss and view (Figure 1) the attitudes of those involved in the habilitation process toward the child and toward the condition. It is possible to accept the child as a person and not to accept the condition, that is, minimize or deny the condition as not really being important and relating to the child as a person without a disabling condition. It may also be possible to accept the condition and not the child, that is, to intellectualize the problem and have the condition, the treatment of the condition, and "hitting all bases" for habilitation while negating the child as a unique entity within himself. How many times have I had to stop a conversation about a deaf-blind child because the conversationalists were beginning to treat the child as an inanimate object? My own emotions become pronounced when I see and hear persons talking about a child, in his presence, as if he were something less than human. If the future is to be met with some balance and maturity, it seems necessary that the child and the child's needs be discussed. It seems necessary that the condition and the future of the condition

Figure 1

ATTITUDES TOWARD THE CHILD AND

TOWARD THE CONDITION



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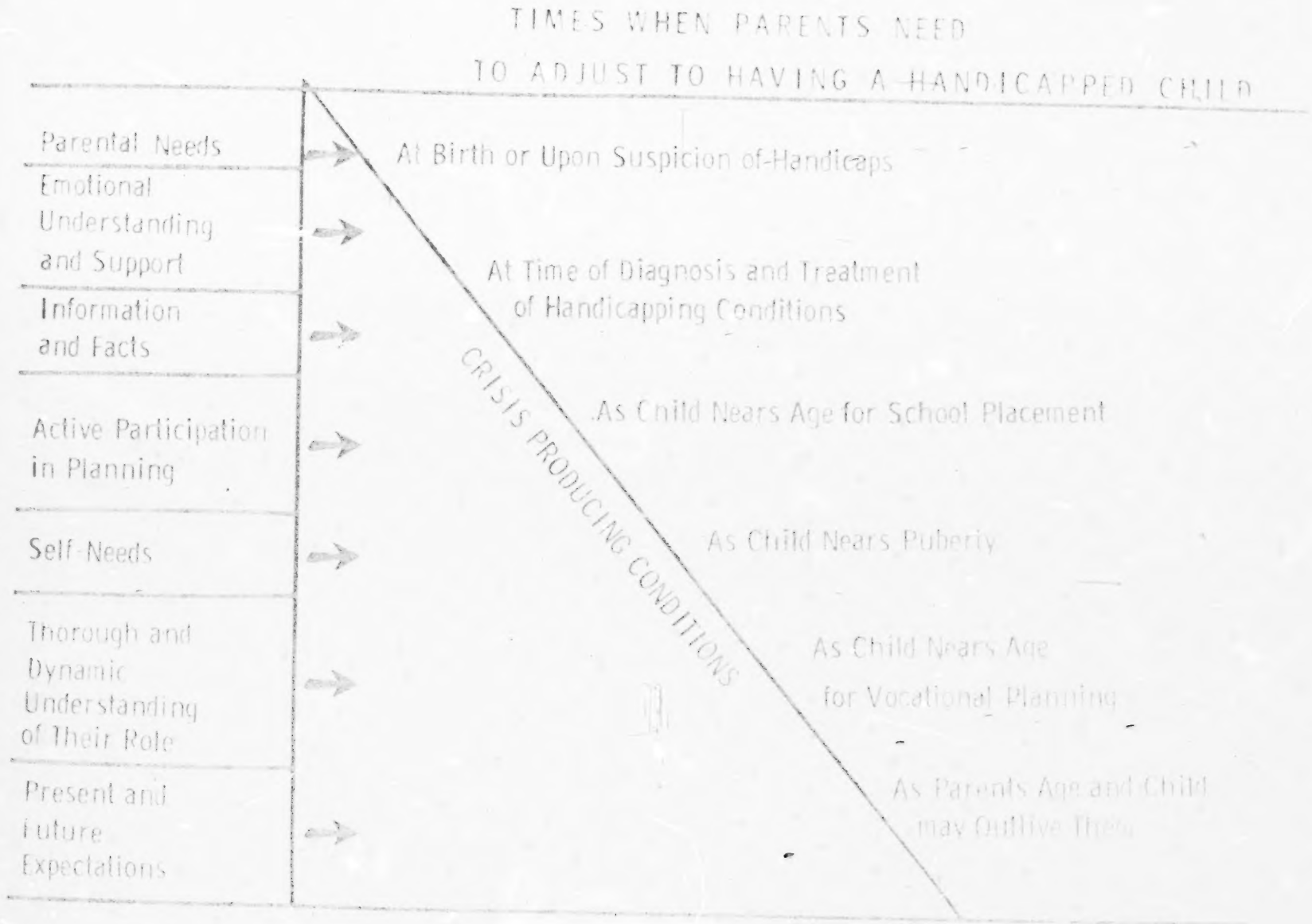
be reviewed so that there are a minimum of brush fires to take the energies of those who could help the situation. If the future is not viewed as an eventual happening, we may be creating problems for ourselves, for the family, and for the child. The least that can be done is to establish some goals which are common to all concerned. The most that can be done is to help the child and family meet the future with some feelings of competency and security.

In light of Barraga's list of parental needs, adjustment seems to be possible for the parents of multihandicapped children. The problem which seems to occur is that adjustment is not a one time thing for these families. Adjustment is not an absolute. Stress occurs at other times in other situations which require the parents to adjust to the threat posed by having a multihandicapped child. There seem to be particular situations in the child's life when re-adjustment is called for on the part of the parents. Figure 2 indicates the chronology when threatening situations arise and when stress is again manifested in the family.

The first of these critical times of stress and need for adjustment is at the birth of the deaf-blind child or at the time a handicapping condition is suspected. Parents often have these apprehensions before they can be verified and this

Figure 2


TIMES WHEN PARENTS NEED
TO ADJUST TO HAVING A HANDICAPPED CHILD
Parental Needs
Emotional Understanding and Support
Information and Facts
Active Participation in Planning
Self-Needs
Thorough and Dynamic Understanding of Their Role
Present and Future Expectations
At Birth or Upon Suspicion of Handicaps
At Time of Diagnosis and Treatment of Handicapping Conditions
As Child Nears Age for School Placement
As Child Nears Puberty
As Child Nears Age for Vocational Planning
As Parents Age and Child may Outlive Them
CRISIS PRODUCING CONDITIONS

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time of concern creates many tensions in the family of not knowing whether their suspicions are true or not.

A second time of crisis seems to occur at the time of diagnosis and treatment of the handicapped child for his disabilities. There is a searching on the part of the parents to comprehend why this happened to them and why their child is impaired. There is a seeking of answers, of facts which Barraga mentioned, and stress occurs as the family and each member tries to place the event in perspective.

A third time of crisis occurs as the child nears the age for school placement, either nursery school or elementary school. Questions arise as to whether the child will have a place for educational activities, whether the child will be accepted by the school and by those in the school, whether the personnel in the school will be able to understand all the concerns which the family has about the present and future of their family member. Often this is a time of labeling the child, of fitting him into categories for placement, or a time when the family finds out that their child will not be accepted into the educational program. What then is available for the child and family? How can parents

learn about their alternatives for services? These questions produce feelings and crises which the parents and members of the family must find coping skills to meet.

As the deaf-blind child or any handicapped child nears the age of puberty, another crisis time happens. Because a child has a disability or mulitiple disabilities, these do not preclude the emotional, social, and physiological changes which occur in puberty. For the impaired child, this may be a time when awareness of differences between himself and others is more apparent. It is a time of isolation and confusion for the deaf-blind child or the multihandicapped child. Emotions are present in this child which may not be communicated to anyone else and may not be understood by the child. The child may have no where to turn and may exhibit this frustration in patterns which physically portray his feelings. The family is also in a time of stress and change. Adjustment of having the multihandicapped person become an adult is a crisis evoking situation for the family. The mythology of disabilities and sex often overwhelms the most astute professional worker. It can be even more destructive to the parent and family of a multihandicapped child. The adultation of the deaf-blind child creates a new set of problems. These problems require a new

set of adjustment patterns. These adjustment patterns again place the family in a stressful situation.

The adultation of the deaf-blind person not only creates a new set of problems in the area of physical growth and development but also in planning and implementation of services. A crisis occurs when the family begins to face the problem of planning for the vocational future of the deaf-blind child. Will career training be possible? What employment will be available when training is completed? This is difficult to plan for the non-impaired person; it is, therefore, even more difficult to outline for the multi-impaired person. How can families be realistic about vocational potential? How can they be helped to gain a perspective on the problem? Vocational rehabilitation for the multihandicapped person seems to begin much further down the line than at age 16, and if this crisis is to be successfully met, concern and pre-planning must also begin with the family much earlier in the child's life than age 16 years.

As the deaf-blind child becomes older, another crisis requires confrontation. This is the realization by the parents that they are finite and will die someday. What is to happen to the deaf-blind child who outlives the parents?

These apprehensions about the continuity of the child beyond the parent lead to another stressful period. Can planning for the future include other members of the family? How does this affect those siblings and other family members in planning their life? What community services are available and will continue to be available for the deaf-blind person left alone? Such questions must be faced by the family and as helping professionals, some solution must be offered, hopefully in the form of the alternatives available to the deaf-blind person. This must be done before the fact, that is, before the parents die and the deaf-blind person is left alone.

To summarize this section of the presentation, it may be stated that:

1. Adjustment is not an absolute. Parents and families of deaf-blind children must face a series of particular crises as well as the unique adjustments which are required to keep the family unit intact. It would seem that discussion of the cycle of adjustment would be more appropriate than a viewpoint of adjustment, per se.

2. There seem to be common parental needs which must be met if the habilitation effort is to reach a maximum level of efficiency. These needs seem to repeat, in different

manifestations, throughout the adjustment cycle for parents.

3. Helping professionals must be aware of the unique needs of parents and family members as well as the deaf-blind child. This may require a different set for the professional who is helping the family, as each crisis may appear to be an undoing of past efforts toward adjustment on the part of the parents. However, this may mean that a new problem has re-opened the adjustment cycle and that it is necessary to re-define the problem and again review the possible solutions for the family.

To illustrate the framework presented here, Mrs. Torrie, Mrs. Yu, and Miss Armstrong will present casestudies of families of deaf-blind children. Mrs. Torrie will discuss the impact of the deaf-blind child on the family as initiator of the feelings parents have toward the child. Mrs. Yu will focus on families of very young children who have been diagnosed as being deaf and blind and the effect of treatment and services on the family. Miss Armstrong will trace the effects which professionals often have on the family in trying to help, but not always knowing what the problem is, as far as stress and adjustment is concerned. These presentations are to raise

questions, which it is hoped, professionals will try to answer through practice and study. Specific questions will be listed by the panel at the end of the presentations.

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